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Multiple sclerosis patients' perspective
on value co-creation

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Abstract

Value co-creation is a young concept in marketing. Through the lens of co-creation, customer is shifting from being a passive recipient to the value co-creator. Co-creation helps the firms to serve better their customers and helps customer to experience more value from the product. Healthcare is among the industries with the highest potential for the value creation.

This master thesis investigated the multiple sclerosis patients' perspective on value creation. Multiple sclerosis affects mostly young people. The existing treatment may only improve the symptoms and consequently improve the quality of life these patients. That's why there is a huge potential in value co-creation with their doctors.

The patients' perspective was tested through a qualitative research. The method consisted of in-depth interviews of ten MS patients and one neurologist from Moldova. It was identified that MS patients focus on activities as cooperating and collating information, are most likely to co-create value through passive compliance practice style, and taking the role to comply with their healthcare provider.

The main implications are for patients from Moldova that might use the results in their further communication when advocating for their needs. The implications are for the healthcare industry as a whole. From one side it emphasizes the need of the changing the public health policy and from the other side, it accentuates the importance of patient empowerment. It also offers healthcare providers insights from the patients' perspectives on how important are the words of encouragement at the stage of the primary diagnosis of MS and after.

Keywords: service-dominant logic, customer, value, co-creation, healthcare

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Chapter 1: Introduction

1.1 General introduction to the topic

Importance of finding ways to better satisfy customers got increased attention since the end of World War II when after the crisis and a tough period of limited access to products people started to have more resources. As the customers' demand was rising, companies were increasing their productivity (Lusch and Vargo, 2015). In the 1950s companies started more research about their customers as the competition was enhancing (Lusch and Vargo, 2015).

Nowadays customers have even more products among which to choose and are much more informed than before (Prahalad and Ramaswamy, 2004). Access to higher education, increased information access, digitalization, and high technological capabilities have as a consequence that customers have higher demands and expectations from a product or service (Steenkamp, 2017). Creating value for their customers is becoming more and more important for managers (Prahalad and Ramaswamy, 2004). Innovative multinational companies are looking for creative solutions to deliver value while answering the modern demand of the customers. Companies are adopting new product-development approaches.

According to an article by Harvard Business Review on product development (Ramaswamy and Francies, 2010), companies have started to engage customers in product development since the late 1990s. For example, the Danish toy manufacturer Lego is considered to be among the pioneers that started encouraging their customers in creating robot toys. Specifically, Lego has established a platform for creating new Lego sets. Anyone can create a toy model according to their preferences and submit the idea of the toy set on Lego's website (www.ideas.lego.com). Afterward, if the idea of the set receives more than 10 000 supporters the idea is qualified to be revised by the Lego Review Board of marketing and design people. The projects selected by the board reach production and are widely distributed across the world for being sold. The author of the initial idea is mentioned on the set materials of the new toy, receives a royalty for sales, and is recognized as the design creator of the product (Kamesh, 2020; Steenkamp, 2017). Kamesh, in his article, argues that this move had helped Lego to be seen as an innovative toy company and to be distinguished from other toy players. In the beginning, the idea of involving customers at the stage of the product designing sounded like a venture, but through time passing it had shown that it turned out to be a worth investing resource and a distinguishing

characteristic for the company (Kamesh, 2020). The fact that it worked very well can also be concluded by judging the worldwide ranking result of Lego. According to Statista “in 2020 Lego was the top-ranked toy brand in the world with a brand value of approximately 6.5 billion US dollars” (Statista, 2020).

Later, many other firms such as Starbucks and Procter & Gamble have also seen perspectives by adopting this kind of new product development. For example, in 2010 Starbucks started their social co-creation strategy through the *My Starbucks idea* site where they collected ideas from their customers (Garon and Williams, 2010). Consequently, Starbucks product strategists used these ideas to create new Starbucks products.

Also, an article by Marketing Week states that on May 23rd, 2013 A. G. Lafley had set out a value creation vision for Procter & Gamble after the failure of the previous CEO Bob McDonald’s (O’Reilly, 2013). The previous CEO was focused more on western countries with premium products and expanding rapidly in emerging countries without a certain and clear strategy. Procter & Gamble’s brand director Roisin Donnelly told Marketing Week: “it’s not about telling people what to do, it’s about listening to people. When we listen to consumers then we win” (Millington, 2015). In practice, Procter & Gamble implemented this by launching the *Connect+ Develop* platform where people outside of the company were encouraged to improve current products or suggest creative ideas for Procter & Gamble (Bernahizli, 2019; Agafitei and Avasilcai, 2015). This new approach to their business model, by becoming more customer-centric, helped P&G to increase the number of new products and double their stock price (Bernahizli, 2019).

The above-mentioned Harvard Business Review article states that Lego, Starbucks, and Procter & Gamble have discovered through this type of relationship (interaction between customers and companies) that creating a better experience for end customers also involves creating better experiences for their employees. For people working for these companies in the R&D departments, the input of the customers through ideas was very helpful and insightful when working on the prospective future products (Ramaswamy and Francies, 2010). R&D specialists could skip the stage of researching the needs of the customers and go straight to the next stage

of finding ways of satisfying the customers' needs that were communicated to them by the customers themselves.

These examples from real-world settings discussed above, emphasize the marketing trend of moving from a goods-dominant logic, which focuses on tangible goods and transactions as the core to a new dominant paradigm (Lusch and Vargo, 2015). Through the lens of the new paradigm of service-dominant logic, Lusch and Vargo define marketing as “the process in society and organizations that facilitate voluntary exchange through collaborative relationships that create reciprocal value through the application of complementary resources” (Lusch and Vargo, 2015, page 408). According to the new dominant paradigm, marketing is about society, collaborative relationships, and creating value by the participants (companies and customers) as the result of their collaboration (Lusch and Vargo, 2015). Literature on the service-dominant logic defines the function of the interaction between the firm and the customers as “co-creation” (Gronroos and Voima, 2013, p.133).

The term co-creation is defined in different ways by different authors (McColl-Kennedy et al, 2012) but the underlying ideas are the same. For example, Prahalad and Ramaswamy (2004) define co-creation as the “joint creation of value by the company and the customer. It is creating an experience environment in which consumers can have active dialogue and co-create personalized experiences” (page 8). Another paper by McColl- Kennedy et al. (2012) define co-creation as “the benefit realized from integration of resources through activities and interactions with collaborators in the customer’s service network” (page 1). In the context of the above definition, from McColl-Kennedy’s point of view, activities are about doing things (e.g., co-learning or providing feedback) and interactions are the ways individuals communicate and collaborate to have a synergy of their resources and help to obtain the desired outcome (Mc-Coll- Kennedy et al, 2012). According to this particular literature, value creation has the highest potential for complex services such as the delivery of healthcare services (Keeling et al, 2021). In the following paragraph, the concept of value co-creation in the specific field of healthcare will be addressed in more detail.

1.2 Specific introduction of the topic

In the context of the added value that both customers and companies can experience as a result of co-creation, value creation can also be experienced by the healthcare customers (in this paper this term will be used interchangeably with patients and at a certain point with MS patients) with outcomes as higher satisfaction of the treatment (Prahalad and Ramaswamy, 2004) and better quality of daily life (McCull- Kennedy et al, 2012).

The healthcare customer is no longer a passive recipient of medical interventions and processes but is more a co-creator of value (Bijmolt et al. 2010) with the healthcare professionals. The healthcare professional is being seen and acting in this case as a facilitator (Gronroos and Voima, 2012) to provide healthcare to customers with the necessary support for receiving value (Sharma and Conduit, 2016). Sharma and Conduit in this paper describe the role of healthcare professionals as a facilitator because they empower and help customers to benefit from the created value if the patient takes part in the co-creation behaviors (co-production, co-development, co-learning, co-advocacy, co-governance).

Despite the growing importance of customer participation in innovation, little is known about the capabilities required to enable healthcare customer participation in healthcare service innovation (Sharma et al, 2014). This might be due to the particulars of the healthcare ecosystem which is facing several challenges (Keeling et al, 2021). On one hand, healthcare policymakers face several challenges as a result of an aging population, the high growth of costs due to the development of new treatments, and customers' lack of access to healthcare (Akenroye, 2012). On the other hand, healthcare organizations are also facing challenges in terms of their healthcare customers who either have high expectations (McCull- Kennedy et al, 2016) or have little knowledge about their disease. This is a challenge contrary to what may happen in co-creation situations in other industries (Berry and Bendapudi, 2007) as it was mentioned earlier in the field of toys, coffee, and others. In these industries customers know very well the products.

Yet, innovation in healthcare through co-creation together with the patients could balance the cost and increase access to healthcare (Omachonu and Einspruch, 2010). It should however be

noted that the financial aspect is not the primary goal of this paper. The main goal of this research is the aspect of quality of life of multiple sclerosis patients.

1.3 Problem definition

1.3.1 Research question

Innovation in healthcare through value co-creation involving the patients could improve the collaboration among all the stakeholders of the healthcare ecosystem: customers, caregivers, providers, suppliers, and policy-makers. Prior research explored the role of the healthcare customer and identified that to empower customers to participate in co-creation there is a need for an adequately prepared ecosystem for change (McColl- Kennedy et al, 2016). For this change to happen it is necessary for both the healthcare customers and the professionals to be empowered to participate in a democratic dialogue when they discuss the resources and priorities during the service interactions (Keeling, et al, 2021).

Another key action that is needed for the change is the ability to know how to manage the change (McColl- Kennedy et al, 2016). Appropriate leadership and managerial processes are needed to make this happen (Payne, et al 2008). Healthcare is a complex system with a lot of norms and specific professional culture which requires consequently adapted managerial solutions such as having a special platform or mechanism where patients may address their questions or suggest their ideas at any time or separate healthcare professionals that will be in charge only of educating and empowering patients to talk about their needs and problems they are facing.

There is literature that talks about team management, insular controlling, pragmatic adapting, partnering as being the practice styles activities that cancer patients use to co-create value so that afterward they benefit from a higher quality of life (McColl- Kennedy et al, 2012). The same paper by McColl- Kennedy et al. argue that the same practices might be applicable for other ongoing diseases, but leaves room for further research to investigate whether practices differ in the context of other chronic diseases as compared to cancer. Therefore, this master thesis will address how applicable McColl-Kennedy et al. practices for a chronic disease such as multiple sclerosis are, with a particular focus on young adults. Therefore, this thesis will address the following main research question:

What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?

1.3.2 Sub questions

From the theoretical approach a literature review will be done to answer the following sub-questions:

-What is value co-creation?

-What are the activities and interactions of each role (patients, HCPs, and stakeholders) that are specifically important in the co-creation process from the perspective of the healthcare consumer in the existing literature?

-What are the prospective benefits of participating in a value co-creation process for customers?

In the practice part the goal is to find the answer for the following two sub-questions:

-What are the activities and interactions of each role (patients, HCPs, and stakeholders) that are specifically important in the co-creation process from the perspective of multiple sclerosis patients?

-Are the results of MS patients' interviews comparable to the outcome of the study by McColl-Kennedy et al. (2012)?

1.3.3 Delimitations of the study

This master thesis will focus on value co-creation in healthcare organizations. It will focus on the theoretical aspect of co-creation, defining the players of co-creation, their roles, activities, and types of interactions. The practical research will come up with suggestions for healthcare organizations from the point of view of MS patients and what they consider to be important in the co-creation process between healthcare professionals and MS patients. There is an assumption that the level of patients' involvement in the co-creation process may differ among the three types of multiple sclerosis (more on MS types will be elaborated in the theory part) and may be influenced by the number of years since the patient was diagnosed with multiple sclerosis. There is also an assumption or hope that the results of this master thesis will help MS patients understand the power of their stories (Ellis, 2021) towards disease awareness and patient voice power among the general population, HCPs, and policy decision-makers.

This master thesis will not investigate the effectiveness of the medication taken by the patients and how a certain type of medication may influence the quality of life of the patients.

It should also be noted that the financial benefits of implementing any of the researched value co-creation practice styles (CVCPS) will not be addressed in this paper. The main goal of this research is the aspect of quality of life of multiple sclerosis patients and identifying the interactions and activities that will lead to a better quality of life for these patients.

Even though we live in a time when everything is going through transformation and digitalization, as for this stage this paper will not include the impact of digital tools as apps.

1.4 Contribution

1.4.1 Theoretical contributions

McColl-Kennedy et al. (2012) discuss the link between the customer value co-creation practice styles of healthcare professionals such as team management, insular controlling, partnering, pragmatic adapting and passive compliance, and quality of life for cancer patients. In the same paper, McColl-Kennedy explains the activities these patients do to contribute to co-creation. Here, several activities were identified: cooperating, co-learning and providing feedback, connecting with family and friends on one hand, and on the other hand interacting with healthcare professionals through changing the ways of doing things.

In 2016, McColl-Kennedy et al. in their paper *The changing role of the health care customer: review, synthesis and research agenda* talks about the patients' roles and how they change across different practice approaches through time passing. For example, in the traditional medical model, which is the most common practice nowadays, the focus is on the disease rather than on the patient. There is a biopsychosocial model where the focus is on the social, psychological, and biomedical sides while treating a patient. A more modern model has shared decision-making when the patient has autonomy in the interaction with the healthcare professional. There is also a model that focuses on the person behind the patient who has feelings, needs, and is willing to make decisions (McColl- Kennedy et al, 2016). Healthcare value co-creation is among the newest models where this master thesis will rely on and contribute to existing literature. Consequently, there is room left for further discussion and

exploration of how patients with chronic diseases such as multiple sclerosis may contribute to co-creation together with healthcare professionals to have a better quality of life and health in general (McColl- Kennedy et al. 2012 and 2014).

Therefore, this master thesis contributes to the existing literature by first identifying the most suitable customer value co-creation practice style for MS patients from their perspective in terms of their activities and interactions with the HCPs in the real-world setting. Second, as it is an interdisciplinary paper, it will offer additional insights into the medical literature about multiple sclerosis. Even though multiple sclerosis is a highly researched topic nowadays there is no clear evidence of what the etiopathogenetic factors are that cause or trigger the disease. There are only drugs that might increase the quality of daily life of MS patients but can't cure it. That's why this paper will contribute to the medical field with activities that might have an additional positive effect on the course of the disease besides the prescribed medications. Even though according to the statistics the incidence of MS is high in the northern countries, there are more than one thousand patients diagnosed with MS in Moldova and the number is increasing each year (Gavriliuc et al, 2017). MS patients from Moldova might benefit from this paper as well as they could use the results of the paper in their further communication with healthcare professionals when aiming to make their voice heard.

Another contribution of the thesis will address a call by the American Marketing Association "to drive positive change and have a bigger contribution to a better world through Marketing" (Chandy et al., 2021) as this paper will use marketing tools and concepts to contribute to making this world a better place for MS patients.

1.4.2 Managerial contributions

This paper will offer contributions as co-creation practice styles (suitable for MS patients) to managers of the medical institutions treating MS patients. Based on the healthcare customer value cocreation practice styles discussed by McColl- Kennedy et al. (2012) and researched among cancer patients, this thesis will investigate if similar results hold for MS patients. Based on the information gathered after the interviews with the MS patients, will be defined recommendations that medical institution managers could use to effectively serve its customers and ideally to save costs.

Moldova, being a developing country, still has a healthcare system with a focus on a goods-dominant logic implying there is a lot of attention on medicines, procedures rather than the patient's experience and needs (Mosca, 2020). A few HCPs who know about the importance of a patient's potential in value co-creation and its outcomes are still hesitating to empower the patients. Building on a paper by Joiner and Lusch (2016), which focuses on the service-dominant logic and emphasizes the perspective of products as being hired to get a job done, meaning that the aim of the product is not just to be in the possession of the customer. The product aims to solve a customer's problem while it is being used and/or after it has been used by the customer. This thesis will provide recommendations on how to evolve in this direction.

It will also provide physicians insights from the patients' perspectives that they could use in their daily work with patients. Relying on Keeling's paper on dialogic engagement and its importance during the consultations provided by physicians to MS patients (Keeling et al, 2021) this master thesis will provide physicians dialogue engagement principles suitable for MS patients. The healthcare industry as a whole will also have to benefit as through patients' input into value co-creation it will be possible to identify ways of spending the resources more rationally.

1.5 Outline of the research

This research is an exploratory study that will answer the question of how healthcare organizations could redesign themselves to empower healthcare customers to participate in value co-creation. The answer to this question will come based on the interactions and activities that are important to exist between MS patients and HCPs from MS patients' perspective. The first part will consist of a literature review on basic concepts of service-dominant logic, value co-creation, roles needed to make a co-creation process, roles' responsibilities, and benefits for each part implicated in it. The next part will focus on the method used to provide an answer to the research question. A qualitative research approach will be set up by interviewing patients that have MS. Based on the interviews, the results will be presented and the research questions will be answered, followed by a general discussion in terms of academic and managerial implications of the given paper.

Chapter 2: Theory

Aiming to better assess the co-creation concept this chapter will start with a literature review on the evolution of marketing as a discipline, the way it has evolved throughout the last 100 years, and where to place the concept of customer value co-creation in the marketing literature. Value co-creation is a young concept that has gained attention only during the past decade (Ind and Coates, 2012). The concept of value co-creation will be discussed within the topic of service-dominant logic by providing the key theories and studies that have been done in this field. The next step will be to review the existing literature on value co-creation and define the responsibilities and activities of the participants in the healthcare industry.

Findings on theories on service-dominant logic and co-creation in healthcare will be helpful to build the theoretical framework, infer the propositions, and prepare the data collection as well as the data analysis method.

As this master thesis takes an interdisciplinary approach, a medical literature review will also be done for the specific population questioned in this paper, who are people living with the diagnosis of multiple sclerosis.

2.1 Co-creation a key concept of service-dominant logic

2.1.1 Transition from goods-dominant logic to the new paradigm of service-dominant logic

More than 100 years ago, marketing started to acquire its academic discipline perspective in journals and professional organizations (Nicolau et al, 2014). According to the existing literature, there are a lot of discussions and debates on marketing periodization which differ based on the views emphasized (context-driven periods or turning points in the events themselves) by the different authors (Hollander et al, 2005). For example, according to Wilkie and Moore (2003), four stages can be highlighted in the evolution of marketing:

- 1900- 1920 “the founding of the field” (page 224): marketing was seen from an economic point of view being orientated to finding ways how to distribute, and sell more;
- 1920- 1950 “formalizing the field” (page 224): marketing was grounded as a discipline and has appeared in publications such as in the American Marketing Association, Journal of Retailing, and Journal of Marketing;
- 1950- 1980 “the paradigm shift” (page 225): triggered by the postwar economic boom and technological discoveries such as TV and computer marketing started to gain importance from managerial and behavioral perspectives. During this stage, the academic field of marketing experienced a huge growth due to the baby boom in the USA and then due to the increased MBA enrollments and graduates. Marketing thoughts during this stage are focused mostly on individual managers and firms.
- 1980- present “the fourth era” (page 225): high growth in the globalization of business education generated high marketing development which leads to another wave of a significant increase in new marketing journals such as *Journal of Macromarketing* (1981), *Marketing Science* (1982), *Journal of Consumer Marketing* (1983), *Journal of Product Innovation and Management* (1984).

Other authors have a slightly different opinion of the periodization of marketing and distinguish the following three stages that are based on turning points in the periodizing marketing history (Hollander et al., 2005; Skalen et al., 2006):

- 1900- 1960: classic marketing perspective (transferring goods from the manufacturer to the customers). It is important to mention that it all started with selling farm products. During this period the focus was on wholesale, retailing, and advertising methods. There were separate principle approaches: the commodity approach that focused on the marketing of the product, the institutional approach that was applied to wholesale and retail, and the third approach was functional describing advertising. The audience of the marketing activities was the general public.
- 1950- 1985: marketing being seen as a discipline within management. During the 1950s the dominant focus started to be marketing management. The utmost importance was

an orientation on the firm and how it should function. As the marketing concept appeared the goal of the managers was to identify ways how to manufacture products that will satisfy the needs of the target customers. As the need for knowing the customers better, segmentation, and targeting tools were developed.

- 1975- present: the beginning of modern marketing or service management. During this stage, both products and services are being seen as processes and outcomes. It becomes important how something is done, delivered, or served to the customer.

A more recent view on the periodization of Marketing is put forward by Philip Kotler and his co-authors. According to his perspective (Kotler et al., 2010) the evolution of marketing can also be expressed in three stages:

- ✓ Marketing-orientated product (1.0): this stage is characterized by aiming to sell more products and is associated with the industrial revolution; another characteristic for this stage is that differences between similar products were made mostly based on price.
- ✓ Marketing-orientated customer (2.0): this second stage is described to have the objective of finding ways to satisfy customers and it is linked to the informational revolution;
- ✓ Marketing-orientated value (3.0): at this stage, the core is the value (heart and soul are becoming important). Among the factors that have triggered this stage is considered to be the technological revolution.

A common feature that can be highlighted among the above views of marketing periodization is that the marketing view has evolved from the goods-dominant logic (tangible goods and transactions being the core) to a service-dominant logic (intangible products and relationships being the core) (Lusch and Vargo, 2015). The authors Lusch and Vargo define the service-centered dominant logic as “a re-oriented philosophy that applies to all marketing offerings, including those that involve tangible output (goods) in the process of service provision” (Lusch and Vargo, 2015, page 4). Service-dominant logic is putting the customer in the center. This customer-centric approach is about collaborating and learning about the customer and at the same time being open and flexible to their needs (Sheth et al., 2000). The role of the customer is shifting from being a passive recipient to the co-producer of service, so being active and

engaged (Lusch and Vargo, 2015). Perceived value is also seen differently, in case of a goods-dominant logic, the producer determines the value (as embodied in the product) and in the case of service-dominant logic, the customer is the one that determines the value based on “value-in-use” (Gronroos and Voima, 2012; Lusch and Vargo, 2015). Lusch and Vargo (2014) put at the core of the service-dominant logic paradigm the 4 axioms (Table 1) which help to understand the essence of the paradigm.

Table 1. Four axioms of the service-dominant logic

Axiom 1	Service is the fundamental basis of exchange.
Axiom 2	The customer is always a co-creator of value.
Axiom 3	All economic and social actors are resource integrators.
Axiom 4	Value is always uniquely and phenomenologically determined by the beneficiary.

- ❖ Axiom 1: Service is the fundamental basis of exchange. The axiom is based on the idea that resources (information, skill, experience) of each actor are used interchangeably between the receiver or the service and the provider of the service, for the benefit of each other. “Service is exchanged for service” (page 15).
- ❖ Axiom 2: The customer is always a co-creator of the value. The core of the axiom lies in the value being created through the interaction of actors. For example, a healthcare professional providing medical service to a patient is co-creating value with the patient, and not independently.
- ❖ Axiom 3: All social and economic actors are resource integrators. Resource integrators are considered to be private resources (friends, family), market resources, and public resources. As a consequence, resource integration occurs indirectly as well between the actors and resources that hold these resources in a network of other resource-integrating actors.
- ❖ Axiom 4: Value is always uniquely and phenomenologically determined by the beneficiary. Through this axiom, value is seen experientially and does not have clear key performance indicators. Each service or product in this context is perceived

differently by each beneficiary of the service or product, and that's why value is seen as uniquely experienced and determined.

In sum, from a service-dominant logic perspective, a firm is seen to have the purpose to serve itself by serving others. The firm can do this by integrating both internal resources and resources it has available through various public market resources. As a result, the firm may obtain new products with added value that are beneficial for others: individuals, families, firms, etc. In this setup, firms cannot create value independently. At the same time, the customer is engaged with the firm in the process of learning about the customer's needs. Through this interaction (between the firms and the customer) both the firm and the customer get to know the customer's needs and decide together on the product that the firm will develop or service they will perform (Jaworski et al, 2006). From the perspective of Gronroos and Voima (2013), the firm's aim is not to look for how to engage customers in the co-creation process, but rather find ways to be involved in their lives. Direct interaction between the customer and the firm is essential in the process of co-creation.

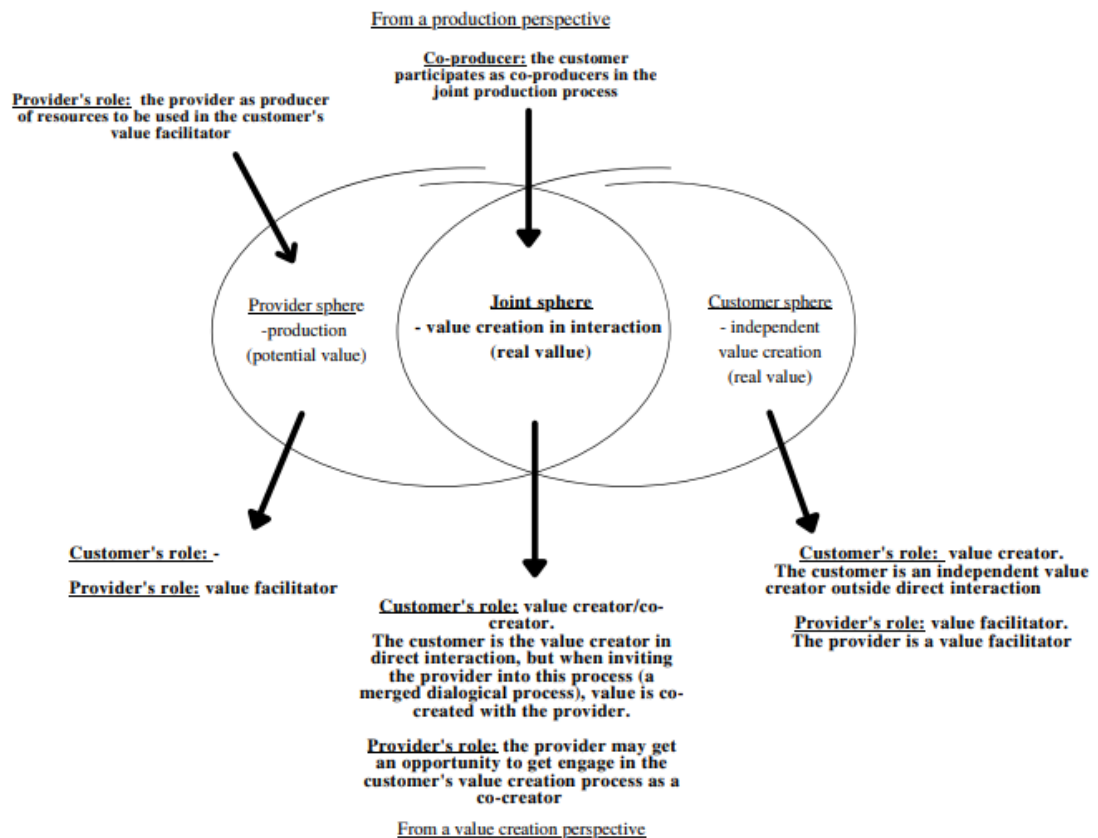
2.1.2 Co-creation definition

In the paper, *Critical service logic: making sense of value creation and co-creation*, Gronroos and Voima (2013) explain the concept of value creation through three spheres which have at the core the level of interaction between the customer and the firm:

- the provider sphere: the firm is responsible for the production of the product for the customer and holds the role of the provider. The firm provides a potential value that the customer may turn into real value in use.
- the joint sphere: the value co-creation process happens through a dialogue between the firm and the customer. In the joint sphere, the customer is also in charge of value co-creation, and the provider may serve as a co-creator of the value through direct interaction and dialogue. As stated by Gronroos and Voima "Co-creation can take place only through direct interactions. If there are no direct interactions, no value co-creation is possible" (page 141).
- the customer sphere is the sphere where the customer is independent of the provider, so no co-creation may happen.

Figure 1 illustrates how the roles of the producer and customer change across the value creation spheres.

Fig. 1 Value creation spheres by Gronroos and Voima (2013)



Despite the fact that existing literature defines the term co-creation in different ways (McColl-Kennedy et al, 2012) the underlying ideas are often the same. For example, Prahalad and Ramaswamy (2004) define co-creation as the “joint creation of value by the company and the customer. It is creating an experience environment in which consumers can have active dialogue and co-create personalized experiences” (page 8). An example of such practice would be involving the customers in the product development stage as it was discussed in the introduction part in the case of Lego, Procter & Gamble, and Starbucks. This is also highly relevant in the healthcare context where the customer may want to engage in active dialogue with the healthcare provider in order to co-create a modality of treatment that would fit the specific

circumstances of the patient. Even though the willingness to participate may differ among patients, it is very important to create an environment where the healthcare customer may feel safe and empowered to influence their own unique personalized experiences with their healthcare providers.

McColl- Kennedy et al. (2012) define co-creation as “the benefit realized from integration of resources through activities and interactions with collaborators in the customer’s service network” (page 1). In the context of the above definition, activities are about doing things (e.g., co-learning or providing feedback) and interactions are the ways individuals communicate and collaborate to have a synergy of their resources and help to obtain the desired outcome (McColl- Kennedy et al, 2012). This definition also extends the concept of value creation to the customer’s service network. For example, healthcare customers may co-create value through interacting with their families, friends and not only with their healthcare providers. Even more, this way of conceptualizing value creation by patients includes patient self-activities such as positive thinking, reframing, and sense-making or emotional labor. Interestingly, according to Keeling et al. (2021), value creation has the highest potential for complex services such as the delivery of healthcare services. In the next paragraph, perceived value in the specific field of healthcare will be addressed in more detail.

2.1.3 Well-being- the highest perceived value by the healthcare customer

Value creation becomes an ongoing process both for tangible and intangible products (Lusch and Voima, 2015) and the customer is the one who extracts value from this experience (Gronroos and Voima, 2013). Moreover, value creation has the highest potential for complex services such as delivery, education, and healthcare (Keeling, 2015).

On a general level, customers’ involvement in value creation impacts their well-being because in this process customers focus besides the economic benefits also on emotional and social benefits that emerge from mental actions (Gronroos and Voima, 2013). In the healthcare setting value, co-creation is associated with the increased quality of life of the healthcare customers. Quality of life is defined by the World Health Organization as “the perception that the individuals have their position in life in the context of the culture and the value system in which they live and concerning their objectives, their expectations, their standards, and their concerns” (WHOQOL Group, 1994, page 41). McColl-Kennedy et al. (2012) defines the quality of life

through integrating “four domains: psychological, existential, support, physical. A detailed description of each domain is discussed in table 2.

Table 2
Four domains of quality of life

Domain	Characteristics
Psychological	the domain that is concerned about feelings regarding being depressed, nervous, worried, sad, and fear for the future.
Existential	this domain concerns an individual’s belief about their life, including the belief that life is meaningful and worthwhile, the goals are achievable, how patients feel about themselves, and if they have a sense of control over their lives.
Support	the domain that is concerned about feeling supported and cared for.
Physical	this domain concerns the individual’s most problematic physical symptoms, such as fatigue, tiredness, pain, weakness.

A great setting example for discussing value creation is the healthcare industry, where value is created by the customers themselves and the firm (in the context of the healthcare industry: the healthcare provider or medical institutions) may only facilitate this process. In the next paragraph, co-creation in healthcare will be discussed in more detail.

2.2 Value co-creation in healthcare

Healthcare is a complex industry where the customer seeks health and well-being (Joiner and Lusch, 2016). Health and well-being are achieved as the value in use generated by the medical product or service delivered by the healthcare professionals. In healthcare, customers do not get value only by possessing that product (medication, diagnostic tests, etc.), rather they experience value (better health status) after using the medicine.

Healthcare is considered one of the most relevant fields (Keeling et al, 2020) to be discussed as grounded in the service-dominant logic where co-creation is being seen as a function of the interaction between the service provider and the customer/patient (Gronroos and Voima, 2012). In this set up the customer is viewed as the value creator (Gronroos and Voima, 2012) through

taking an active part in co-creating the value through the service delivered by the healthcare professionals (McColl-Kennedy et al, 2016).

A synthesis of the role of the healthcare customer has been made by McColl-Kennedy et al. (2016) who discussed ten practice approaches of how the role of the patient has evolved starting from the traditional medical model (focus being on the disease), a model that has been the most predominant practice approach, then patient participation (which emphasizes the patient’s right for information), shared decision-making (patient autonomy in the healthcare interactions), then person-centered care (where the patient is viewed as a person with needs and feelings) to the latest, the healthcare value co-creator. More detailed information on the 10 practice approaches of the role of the patient is described in table 3.

Table 3
Ten practice approaches emphasizing the role of the healthcare customer and the roles of the respective healthcare professionals

Practice approach emphasizing the role of the patient	Description of the model
Traditional medical model	HCPs focus on the disease rather than on the patients. The HCP is seen as an authority and decision-maker, and the patient is a passive actor.
Biopsychosocial model	It considers social, psychological, and biomedical aspects in the treatment of the patients
Patient centeredness	This model focuses both on the disease and the patient as a person, respecting the patient’s values and needs, enhancing the patient-professional relationship and commitment, involving in care and decision-making
Patient participation	It emphasizes the patient right to information, choice, voice, and safety
Shared decision-making	This model encourages patient autonomy in interactions with the HCPs, making medical decisions on mutual agreement between the patient and HCPs. The distinctive feature of this model is the mutual process when all the participants are being active.
Patient empowerment	According to the World Health Organization, a patient in this type of model gains more control over the decisions and

	actions affecting their health. Patients understand their role, they receive knowledge and skills from their HCPs in order to be capable to perform actions affecting their health.
Person-centered care	This model emphasizes the person behind the patient with feelings, needs, and will to decision- making and puts more emphasis on the partnership between the patient and the doctors
Collaborative care	This model provides a comprehensive framework for collaboration between the patients and HCPs.
Self-managed care	It acknowledges the patient's activities both inside and outside of the healthcare setting.
Healthcare value co-creation	The customer is an active co-creator of value and a collaborator in care, even though the type of practices within this model may vary depending on the way the patient perceives the benefits. The patient co-creates value with the HCPs and others from their network or ecosystems.

The healthcare value co-creation model is the most recent approach that has emerged from service research where the customer is being seen as the co-creator of value together with their healthcare providers or others from their network or ecosystem. According to this approach, patients co-create value in different ways and integrate different sets of resources. Each patient is unique depending on their individual circumstances, stage of the disease, and the way it affects their daily life and as a result, patients tend to co-create value in different ways (McColl-Kennedy et al., 2012, 2016). McColl-Kennedy et al. (2012) have explored the different practice styles that patients may adopt while taking part in the value co-creation process based on their circumstances. Specifically, the authors asked patients suffering from cancer directly about their interactions, activities, and their quality of life. This work highlights the importance of the patient's role and the way each patient interacts with others and that not all patients may have the same motivation to participate in customer value co-creation. There may be patients with the same level of motivation but their preferred style of interaction may differ based on their particular view of their role as a resource integrator in the co-creation process. Consequently, based on their study, the authors identify five groups of customer value co-creation practice styles: team management, insular controlling, partnering, pragmatic adapting, and passive

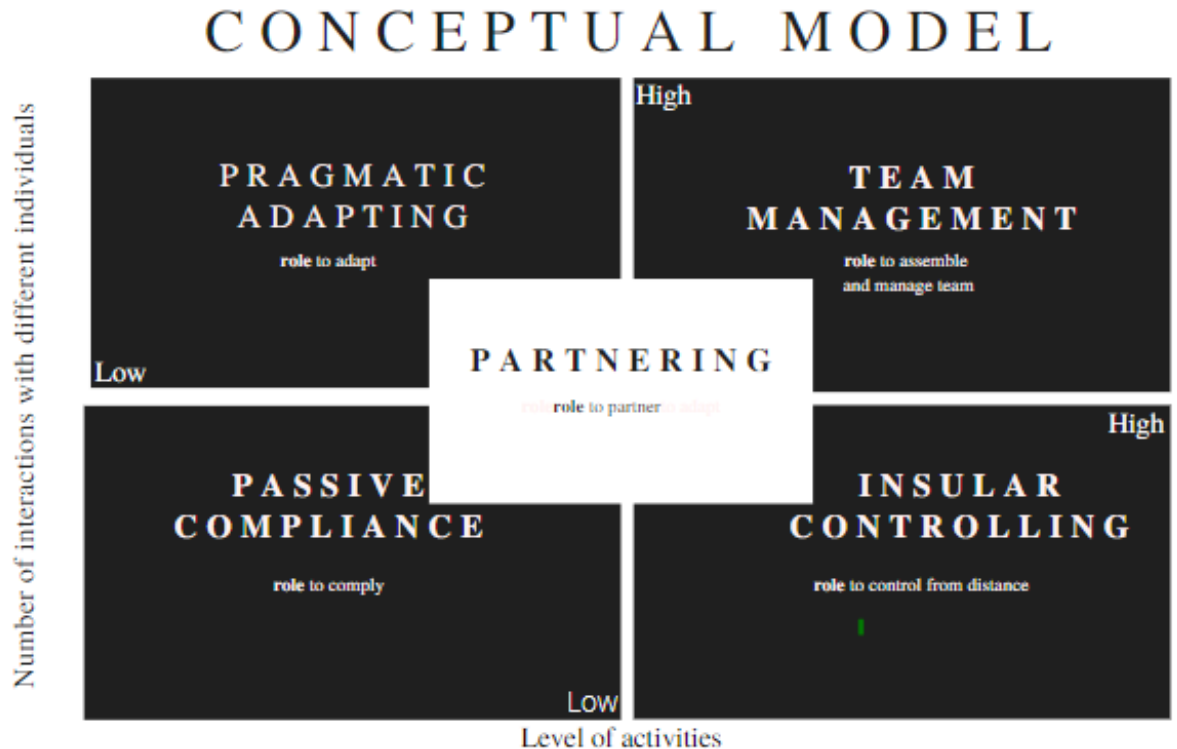
compliance (McColl-Kennedy et al, 2012). A detailed description of each practice style is discussed below in table 4.

Table 4
Customer value co-creation practice style, according to McColl-Kennedy et al. (2012)

Customer value co-creation practice style	Activities
team management	<ul style="list-style-type: none"> ● the high number of interactions and activities ● activities include: cooperating, collating information, co-learning (sharing and providing feedback), combining complementary therapies, connecting with family and friends, HCPs. ● engaging in cerebral activities: positive thinking, reframing
insular controlling	<ul style="list-style-type: none"> ● the high level of activities but low number of interactions ● activities include: cooperating, collating information, co-learning, combining complementary therapies ● communication is not open ● patients are self-focused and control everything from a distance ● cerebral activity: emotional labor
partnering	<ul style="list-style-type: none"> ● medium level of activities and a medium level of interactions ● activity as collaboration is primarily with key service provide ● other activities include collating information, combining therapies ● cerebral activity: positive thinking
pragmatic adapting	<ul style="list-style-type: none"> ● low level of activities, but a high number of interactions ● activities: largely cooperating, collating information, connecting ● cerebral activity as positive thinking, reframing, and sense-making ● patients tend to be adaptive and open to change
passive compliance	<ul style="list-style-type: none"> ● the low number of interactions and activities ● interaction is limited to one source: the doctor ● the patient is following the doctor's orders ● the patient does not practice questioning the doctor

This paper is one of the core articles on which this thesis relies and will use the conceptual model (Figure 2) built by McColl-Kennedy et al. to identify the value co-creation practice style used by MS patients.

Fig. 2 Conceptual model based on McColl-Kennedy CVCPS



McColl-Kennedy et al. (2012) also link each practice style to a certain degree of quality of life: high, moderate, and low. For example, patients adopting the team management practice style usually experience a relatively high quality of life; individuals adopting passive compliance demonstrate a relatively low quality of life; insular controlling is characterized by the relatively low quality of life; partnering- demonstrate relatively high levels of quality of life, pragmatic adapting- this CVCPS is associated with moderate quality of life.

In the empirical part quality of life of MS patients will also be investigated having the foundation of the same paper.

Table 5
Summary of customer value co-creation practice styles and quality of life

Style	Quality of life
Team management	Psychological- high positive Existential- moderate to high positive Support- high positive Physical- low to moderately negative
Insular controlling	Psychological- moderately negative Existential- low positive Support- low positive Physical- low to moderately negative
Partnering	Psychological- moderately to high positive Existential- moderately to high positive Support- high positive Physical- low to moderately negative
Pragmatic adapting	Psychological- moderately positive Existential- moderately positive Support- moderately to high positive Physical- low to moderately negative
Passive compliance	Psychological- low positive Existential- low positive Support- low to moderately positive Physical- low to moderately negative

It is interesting to have a look at prior research that reveals the behaviors (table 6) through which patients may co-create value. According to Sharma and Conduit (2016), there are five co-creation behaviors at the core of value co-creation in healthcare: co-production, co-development, co-learning, co- advocacy, and co-governance. The core co-creation behaviors of the co-creation in healthcare are explained in Table 6 below.

Table 6
Co-creation behavior of value co-creation in healthcare, according to Sharma & Conduit (2016)

Co-creation behavior	Activities
Co-production	Customers/patients participate in the process of receiving care
Co-development	Customers/patients contribute with resources to enhance the provider's offering
Co-learning	Customers/patients and organizations learn from each other and share information they hold
Co-advocacy	Customers/patients are involved in promoting the organization and actively engaging other customers/patients
Co-governance	Customers/patients are involved in elaborating the organizational system and represent the organization on different levels such as Board, committees, etc.

The authors emphasize the activities that facilitate the process of co-creating: dialogue, shared market intelligence, mutual capability development, and shared decision making. Mutual respect, empowerment, and mutual trust are being highlighted as three values that are needed within the healthcare organization for value co-creation. Similar concepts on co-creation behavior are discussed by Tommasetti et al. (2016) who also considers that for users (customers) the value of co-creation is immaterial in nature. The terminology differs and has at its core eight activities: cerebral activities, cooperation, information research and collaboration, the combination of complementary activities, changes in habits, co-production, co-learning, and connection.

They also provide evidence that in some situations the customer-HCP interaction may also lead to co-destruction which might be due to power imbalance, choice restriction, reluctant customer, or a negative perception of the care service (Tommasetti et al, 2016). To minimize the chance of these incidents it is of high importance to understand and implement the recent concept of dialogic engagement (Kent and Taylor, 2018) which focuses on the quality of the dialogue between patient and their healthcare provider. The concept of dialogic engagement has its foundation in the understanding of the inputs of each participant during the interaction that facilitates shared meaning (Keeling et al, 2021). Keeling provides further understanding of dialogic engagement through three principles: dialogic democracy, intellectual honesty, and

affirmation (Table 7). This first principle is dialogic democracy. According to this principle, participants share knowledge with each other and share resources. The same as sharing resources is the responsibility of all the participants, the same tensions and conflicts that may occur during the intervention is an equal responsibility of all the participants involved in the interaction. The second principle is intellectual honesty. It requires free access to information, offering informed choice by the HCPs, and answering all the questions the patient has regarding the treatment, so that in case of necessity there may occur a respectful debate between the patient and the HCPs. It requires an environment where the patient feels safe to share their perspectives and concerns. The third principle is affirmation. It is based on the acknowledgment of others' experiences and rights with a focus on social-emotional aspects.

Table 7
Three principles of dialogic engagement, according to Keeling et al. (2021)

Principles of dialogic engagement	Co-creation mechanism
<u>Dialogic democracy</u> recognition of the equality of all participants involved	relational responsibility signal equality reciprocal knowledge building
<u>Intellectual honesty</u> there is room for debate and allows the presence of a non-expert perspective	raise customer/patient awareness that truth may be challenged and discussed questions about treatment
<u>Affirmation</u> respect for others realities and the right to express experiences and emotions	self- expression promote confidence for open expression

A dialogue of good quality may be achieved through four cerebral activities: positive thinking, tolerance, expectations, and trust of those involved in the dialogue (Tommasetti et al, 2016).

2.3 Stakeholders benefits from co-creating value in healthcare

The benefits of changing the role of the patient from a passive one to the active one who is participating in value co-creation are as follows (McColl-Kennedy et al., 2016):

- some customers may see benefits from engaging in more activities and interactions concerning their health (McColl-Kennedy et al, 2016);

- increase patient satisfaction (Lorig et al., 2008; Jahng et al., 2005);
- better health outcomes (Vetter-Smith et al., 2012) which lead to lower mortality rate;
- better quality of life (Street and Voist, 1997);
- reduced risks of further diseases (Kinmonth et al., 1998);
- improved glucose control (Anderson et al., 1995);
- decreased drug usage (Steward, 1984).

As mentioned above, co-creation is a key concept of service-dominant logic. It is a new paradigm that has at its core intangible products and relationships. Even though more recent literature defines service-dominant logic as “a re-oriented philosophy that applies to all marketing offerings, including those that involve tangible output goods in the process of service provision” (Lusch and Vargo, 2015, page 4). At the same time, not only the firm is the one that changes the perspective of viewing their relations with the customers, but the customers themselves also change their role. The customers are shifting from a passive recipient of the co-producer of service to an active and engaged co-creator of value (Lusch and Vargo, 2015). Direct interaction between the customer and the firm is essential in the process of co-creation.

This master thesis focuses on value co-creation in healthcare as this industry is among those industries with the highest potential for value co-creation (Keeling et al., 2021). Through the time passing the role of the customer has evolved (McColl-Kennedy et al., 2016) a lot from the passive actor (traditional medical model, table 2) to the modern active role of value co-creator (healthcare value co-creation model, table 2). Patients co-create value through different behaviors, such as co-production, co-development, co-learning, co-advocacy, co-governance (Sharma and Conduit, 2016). The patient's motivation to co-create value is mostly well-being, but every patient is unique and has different circumstances and levels of motivation to co-create value. McColl-Kennedy et al., 2012 have identified five customer value cocreation practice styles (CVCPS) among cancer patients and each style is characterized by a different level of quality of life: low, moderate, or high.

This master thesis in the empirical part will compare the applicability of the elaborated conceptual model by McColl-Kennedy (Fig.1) to the context of exploring value co-creation of

multiple sclerosis patients. This disease affects mostly young adults and there is currently no treatment available that could cure the illness. Yet, there are treatments that can improve the symptoms and consequently improve the quality of life of MS patients. That’s why there is a huge potential in improving the quality of life of these patients through value co-creation with their healthcare providers. In the next paragraph, some key medical background information on the types and symptoms of multiple sclerosis is provided.

2.4 Multiple sclerosis: facts, types, and symptoms

Multiple sclerosis is an autoimmune system disease that occurs because of the inflammation which attacks myelin (Loren, 2003). The factors that may cause the disease are still unknown. Patients are not born with it. It usually appears as a consequence of the environmental factors that may play a role as triggers in the people genetically predisposed to the disease (Loren, 2003).

Commonly accused symptoms of MS patients are fatigue, numbness and tingling, difficulties with balance and dizziness, stiffness or spasms, tremor, pain, bladder problems, and bowel trouble. The symptoms occurring for each MS patient are unique, that's why the combinations of the above symptoms may vary among patients, and not every patient will experience all the above symptoms. Multiple sclerosis is used to be called “the disease with 1000 faces” because there are no two similar MS patients”.

There are three types of multiple sclerosis: relapsing-remitting MS, primary progressive MS, and secondary progressive MS; more detailed characteristics of each type are provided in table 8.

Table 8
Types of multiple sclerosis and their characteristics, Gavriliuc (PCN-287; 2017)

Type of the multiple sclerosis	Characteristics
Relapse remitting (RR)	-the most common form, 70% of incidence -it is characterized by relapses after which patient may recover totally or partially -this form of MS has the best prognosis -it is common among 20-30 years old population
Primary progressive	-15 % of incidence

	<ul style="list-style-type: none"> -the relapses are progressive from the very beginning which lead to difficulties in walking and to disabilities within 2 years after the diagnosis -it affects mostly the spine -there are many active outbreaks on NMR (nuclear magnetic resonance) -appears mostly at 40 years old, but exceptions may happen
Secondary progressive	<ul style="list-style-type: none"> -it usually appears after 10 years of relapse remitting MS -the recovery of the relapses may be partial or total, but the progression of the disease happens even in between the replaces -appears mostly at 35 years old, but exceptions may happen

Due to the biological treatment, the symptoms of the chronic disease may be decreased (McCull- Kennedy, 2012). Patients may also improve psychological well-being and have greater satisfaction with their healthcare professional (physician) if engaged in shared decision making (Aschcroft, et al 1986; Fallowfield et al 1990) and potentially enjoy a better quality of life (McCull- Kennedy, 2012).

Multiple sclerosis (MS) is one of the most disabling neurological diseases among young adults. It often affects adults aged between 20 to 40 years (Loren, 2003). The impact of a multiple sclerosis diagnosis on a person's life is tremendous as it affects their social, professional, financial, and health status (Rao, 1991). There is a high incidence of divorce among the patients after being first diagnosed with a form of MS. Many MS patients complain that they were forced to leave their jobs after receiving the MS diagnosis. There is a high percentage (40-50%) of patients suffering from depression during the disease evolution (Stenager et al, 1992). Moreover, a suicide risk of fifteen percent has been identified among those suffering from depression. Suicide may occur within a few years after the diagnosis or as a consequence of the relapse progression (Sainsbury, 1986). There is also evidence that shows that life expectancy is shortened by 5 to 11 years because of the consequences of the illness (Kingwell et al, 2012).

This master thesis attempts to assess the potential that can be in improving the quality of life of multiple sclerosis patients through co-creating value with their healthcare providers. This will

be done by exploring the application of the customer value co-creation practice styles elaborated by McColl- Kennedy et al. (2012) to multiple sclerosis patients. This paper will investigate what activities and interactions multiple sclerosis patients use to co-create value. However, there are assumptions that there could be differences in co-creating value between the multiple sclerosis patients (that are investigated in this paper) and cancer patients (that were investigated in McColl-Kennedy's paper).

Multiple sclerosis patients mostly tend to be alone and sometimes even avoid social contact. It is common for MS patients to not share their feelings and problems with others, sometimes they even feel ashamed to confess that they are diagnosed with MS. That's why It is expected that multiple sclerosis patients' most preferable customer value co-creation practice style will be insular controlling (high level of activities but a low number of interactions) and will differ from the cancer patients, who have the passive compliance CVCPS according to McColl-Kennedy et al. (2012).

It is expected that independently of which CVCPS a patient may adopt, their psychological domain of quality of life will be low (Kingwell et al., 2012). Contrary to which is in case of cancer patients who rate high positively to moderately the psychological domain in case of team management, parenting, pragmatic adapting.

It is expected that both MS patients and cancer patients have the common activity of collating information.

It is also expected that the quality of life of MS patients is influenced by their type of MS. There is a probability that those diagnosed with PPMS will have a primarily low quality of life and those diagnosed with RRMS will have a moderate to high quality of life. It will also influence in the same way their willingness to be active and take the role of co-creator in the process of value creation with the healthcare professionals.

The detailed method of how it was investigated is provided in the next chapter.

Chapter 3: Method

To answer the research question of this master thesis: *What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?* qualitative research has been done. The method applied is structured in-depth interviews with multiple sclerosis patients.

3.1 In-depth interviews

In-depth interviews were the main tool for data collection that aimed to investigate the value co-creation between multiple sclerosis patients and their healthcare providers, focusing mainly on the perspective of the patients. The structure of the interview had the goal to facilitate reflection on the experience of interaction between patients and doctors. The questions used for the interviews with patients are based on two papers McColl-Kennedy et al. (2012) and Dunning (2020) and adapted to the multiple sclerosis context. The questions asked during the interviews with the MS patients were about the patient experience since the diagnosis and their number of interactions and activities with their healthcare providers. The research questions driving the interviews were the following:

- *What has been the hardest thing for the patient on their path with MS?*
- How often does the patient visit their neurologist?*
- To describe their recent visit to their neurologist? To elaborate on 1 positive and 1 negative aspect from the patient's point of view that the patient can recall during the recent visit to their neurologist?*
- What could the HCPs additionally do based on the existing resources that would lead to better communication between the HCPs and the MS patients, from patients' perspectives?*

The interview protocol guide used for the interview with patients is provided in Appendix A and the full questions funnel is provided in Chapter 5, Table 9.

Interviews with patients were conducted until the information redundancy was achieved as recommended by Lincoln and Guba (1985). A summary of the interviews with the patients is provided in Appendix D.

As healthcare providers are also participants in this process, a neurologist from the Institute of Neurology and Neurosurgery in Chisinau was also interviewed to get more insights from a provider's perspective. However, the main focus was on the patients' perspective and this interview provided additional information. The full interview protocol guide is provided in Appendix D. The questions used for the interview with the neurologist are based on the Dunning (2020) paper and are provided in Appendix F.

3.2 Populations

The populations for this research consisted of ten multiple sclerosis patients from the Republic of Moldova, who were currently receiving prophylaxis treatment for MS (6 patients), but also those who were not following any prophylaxis treatment (4 patients). All the participants in the research have a long history of the disease, the minimum is 7 years since the multiple sclerosis was diagnosed and the maximum is 34 years. Both genders participated in the research on an equal footing: 5 women and 5 men. The focus was on young adults: the youngest participant was 33 years old, the oldest was 56 years and the mean age was 38 years. Even though the majority of the participants were young adults, only 50% of those interviewed are employed. The number of in-person meetings between the patients and their doctors varied: there was a patient who said that they do not remember when it was, mentioning that in the last six years it happened around three times. Those who are not following a prophylaxis treatment for MS mostly said that they go to visit their neurologist only when relapse happens and this depends on the type of MS the patient has. Most active in terms of interaction as in-person consultation with their neurologists turned out to be patients who are involved in clinical trials for testing new medication. They answered that they visit their neurologists once in one, two, or three months depending on the type of clinical trial and how often they are supposed to receive the therapy.

3.3 Setting

The interviews with MS patients were held either online, using a zoom meeting/ a Viber call, or offline if the participants were fine to meet in-person taking into consideration the epidemiology situation because of the COVID-19 pandemic. In both cases, the interviews were recorded and the researcher took notes during the interviews if the respondent agreed with that.

The duration of the interviews varied from 60 minutes to 120 minutes. Most of the interviews were held in Romanian as it was the most convenient language for the patients, and only two interviews with patients were held in Russian as they are Russian speakers but living in Moldova. After the interviews, all interviews were translated into English, as part of phase 1 of the data analysis: familiarizing with the data, which will be discussed later in this chapter.

The interview with the neurologist was held in person at the Institute of Neurology and Neurosurgery in Chisinau, Moldova. The researcher took notes during the interview based on the consent of the doctor (Appendix F). The interview was in Romanian and lasted 150 minutes. After the interview, the researcher translated the notes of the interview into English.

3.4 Recruitment

The recruitment of the MS patients was done in person or by phone or via email. At this stage, the relevance for participants to take part in the research and the value it can offer them was stressed. An encouraging aspect for MS patients was that the interviews will be handled anonymously and that their names will not be disclosed in the paper or anywhere else. The consent form is provided in Appendix B.

The recruitment of the neurologist was done in person at the Institute of Neurology and Neurosurgery in Chisinau, Moldova. The interview with the neurologist is also anonymous and the name of the doctor will not be disclosed in this paper.

After the interview, the neurologist helped with recruiting a few additional MS patients for the empirical research.

3.5 Data analysis

As mentioned earlier, the data corpus was collected through interviews that consisted of open questions. For qualitative data analysis, the thematic approach by Braun and Clarke (2006) was used because it offers an accessible and at the same time flexible approach to analyzing qualitative data.

There are many qualitative approaches that are complex and nuanced (Holloway and Todres, 2003). Generally speaking, qualitative methods can be divided into two big groups. Within the first group, there are methods that are linked to a particular theoretical and/or epistemological

perspective. For instance, the interpretative phenomenological analysis (IPA; Smith and Osborn, 2003) and the narrative analysis (Murray, 2003; Riessman, 1993). The second group of the qualitative methods is mostly independent of theory and epistemology. That's why these methods give the opportunity to be applied across a range of theoretical and epistemological approaches. Thematic analysis is among the approaches from the second group (Braun and Clark, 2006). This method implies analyzing data through identifying repeating patterns or themes of potential interest within the data and coding it. There are no exact rules to be applied in the frame of the thematic approach because it is characterized as a recursive process, where the analysis may go back and forth. Braun and Clark (2006) recommend a six-phase process of thematic analysis. Please find below the six phases used in the analysis of this paper:

Phase 1: Familiarizing with the data

All the data gathered during the interviews referred to the data corpus of the analysis. The first phase of the thematic analysis had started immediately after each interview when the researcher translated the collected data (data corpus) into English. Translating the collected data into English was done as part of the familiarizing with the data phase. As recommended by the authors Braun and Clarke (2006) and as part of the first phase, from the corpus data only relevant information related to the context of this paper was selected, which is referred further to as data set.

Phase 2: Generating initial codes

The next phase began with re-reading the data set once again and generating the initial list of ideas of what is interesting about them. Codes were generated manually from these ideas. After the data set has been coded, a list of different codes was obtained.

Phase 3: Searching for themes

The third phase started with searching for themes across the existing codes. This was done by analyzing the codes and identifying how different codes could be combined to form a common theme.

Phase 4: Reviewing themes

This phase involved refining the themes, as some candidate themes were not really themes because there was not enough data to support them or other themes that had collapsed into other themes. This phase was similar to editing the written work.

Phase 5: Defining themes' names

Defining names for the identified themes were made through finding the essence of what each theme is about.

Phase 6: Writing the report

This phase started when there were fully worked-out themes and involved the writing of the final report of the data analysis.

As a result of analyzing the data set, four central themes were identified: a new reality, it is the healthcare system, avoidance, and communication. A more detailed explanation of the identified themes and sub-themes will be discussed in the next chapter.

Chapter 4: Results

Patients' responses were analyzed for common themes and coded based on the thematic analysis approach (Braun and Clarke, 2006). At the stage of phase five four themes were defined and named. Then after the process of refinement, it was identified within each theme, one sub-theme. The resulted themes and corresponding sub-themes identified are the following:

1. *A new reality*
sub-theme: multiple sclerosis experts
2. *It is the healthcare system*
sub-theme: the value of cooperation
3. *Avoidance*
sub-theme: lack of the community
4. *Communication:*
sub-theme: psychotherapist

4.1 A new reality

One of the main themes identified is linked to the lived experience of multiple sclerosis patients. Ninety percent of the interviewed patients mentioned that they had not had any health problems before the primary diagnosis of multiple sclerosis was announced. They did not have any close interaction or contact with the healthcare system before being diagnosed with multiple sclerosis. A new reality that is difficult to accept at the beginning is a central theme identified after reviewing the patient's interviews. One patient commented:

“After I received the diagnosis of multiple sclerosis, I had to review my priorities. My life had changed drastically. I realized how important my family is, and health has become the number one priority in my life.”

Another patient commented the following:

“I was only twenty-one years old when I was primarily diagnosed with multiple sclerosis. I was a student at that time. I was very active from the aspect of physical activities. I used to practice

boxing, running, and workouts at the gym. After the diagnosis, my life had changed a lot. I had to go often to see my doctor, moreover because of the relapses I had to stay in the hospital for ten to fourteen days sometimes. Obviously, there was no room for practicing any sport.

In Moldova, at that time there were not many options for treatment and I didn't have enough financial resources to go abroad for modern treatment. What have I done? - I have completely changed my lifestyle, meaning that I started a gluten-free diet (quite challenging to follow both financially and mentally). Also, I started to practice another type of physical activity that has the purpose to rehabilitate, a kind of yoga for rehabilitation.

Multiple sclerosis is a disease that changes a person's life completely and forever, unfortunately."

In this new reality, when their quality of life is negatively affected because of the symptoms of the disease and its relapses, patients start to look for more information about their disease, treatment options, and different complementary activities that could lead to better health outcomes despite the diagnosis. Step by step they become experts in the field of multiple sclerosis. A sub-theme that emerged from the theme of "a new reality" is multiple sclerosis expert. No one else knows the disease better than the patients themselves who have to leave with it every day. One patient commented:

"Once I was diagnosed with MS, I know the best what are the symptoms and what are the problems that a person living with MS has to learn how to deal with every day. This was the reason that drove me to found the patients' organization in 2015. Unfortunately, at this moment because of the worsening of my health status, I don't have the possibility to take care of the organization and organize any events."

- sub-theme: multiple sclerosis experts

Patients with multiple sclerosis diagnosis know their diagnosis, disease, symptoms, and treatment options very well. Most of them recalled exactly the definition of multiple sclerosis when asked to define it: an inflammatory demyelinating disease of the central nervous system that is characterized by inflammation, demyelination, and degenerative changes. There were a few who defined multiple sclerosis in an original way such as

“the betrayal of the body, you no longer feel that you can control it, it is like your body is working against you and you can’t do anything with that. After MS diagnosis, my life changed 360 degrees.”

Another patient described multiple sclerosis as

“an obstacle in life, with each relapse it will get worse and worse; with each relapse, your life will change little by little at first with small difficulties with the mobility, but after a few years you will get to the point of needing a walking stick for doing your grocery.”

One patient recalled what they had lost after MS diagnosis which changed their life a lot:

“I lost my job, because of the diagnosis. Unfortunately, my manager did not know much about this diagnosis and started to have doubts about my cognitive capabilities. I have to admit that it is true that MS patients can’t concentrate for a long period of time as others do, but if trained daily I could stay concentrated for around 4 hours.”

Multiple sclerosis diagnosis affects the lived experience of an individual, the effect is even more vivid because it affects young people who used to be physically active. After the diagnosis, their lifestyle changes tremendously. One patient said:

“Of course, I know all the new updates in terms of the innovative treatment for multiple sclerosis. I want to go back to my previous life so I keep up with all the news that comes my way regarding the disease.”

Based on the fact that multiple sclerosis patients learn constantly and look for information about multiple sclerosis it was concluded that a common activity for MS patients is collating information. Collating information is common for all five customer value co-creation practice styles: team management, passive compliance, partnering, insular controlling, and pragmatic adapting (McKennedy et al., 2012).

4.2 It is the healthcare system

Another central theme that was identified is “It is the healthcare system”. This theme was quite often mentioned by the patients and also by the interviewed neurologist in the context of the limitation that the healthcare system in Moldova has. The neurologist punctuated the following:

“The healthcare system in Moldova has critical limitations in terms of innovative prophylaxis treatment. This could be solved only through changing the public health policy in Moldova. Also, as we are talking about what the healthcare system could do better to improve the doctors’ practice and the health of MS patients then I would also add the complex multidisciplinary approach to the MS patient and their problems.”

Interviewed multiple sclerosis patients have the tendency to comply and often comment that their healthcare providers are cooperating based on the existing restricted possibilities of the healthcare system in Moldova. One patient commented that the system hasn’t changed since Soviet Union time:

“The Healthcare system in Moldova has very good healthcare professionals in the neurological field. I have received proper treatment for my neurological problem. At the same time, I have to admit that I have been walking through the halls of the hospitals since I was ten years old, and the soviet system is still present in the healthcare system in Moldova. This is the situation.”

Another patient answered the question regarding their communication with the doctor the following:

“Based on the existing resources, my doctor is very considerate during our meetings. They are doing their best taking into consideration that there are so many patients and the budget is so limited. Also, unfortunately, the healthcare system does not have enough resources to provide innovative treatment for multiple sclerosis. That’s the reality of the system that we have to accept.”

Multiple sclerosis is a disease with a variety of symptoms, there are no two similar patients with similar symptoms. Another patient commented:

“I am lucky to have very good doctors who are empathetic and considerate to my problems and challenges I face because of multiple sclerosis, but unfortunately in Moldova, there does not exist a multiple sclerosis center with specialized HCPs mainly in this problem. Our healthcare system can’t allow such a center, because of the limited resources both financially and professionally.”

As can be inferred from the above comments by the patients, most of them tend to adopt the role of complying and just accept the limitations of the situation or the healthcare system. The situation when the patients tend to adopt the role to comply is typical for the passive compliance practice style (McColl- Kennedy et al., 2012). Among the interviewed multiple sclerosis patients four out of ten tend to adopt the passive compliance practice style in the process of value co-creation with their healthcare providers.

Despite the limitations that are undoubtedly present in the healthcare system in Moldova, according to patients’ words, cooperation with their neurologist is the activity that helps them at the moment of the primary diagnosis and later when they need encouragement after the relapses.

- sub-theme: the value of cooperation

A sub-theme regarding the healthcare system that was identified as common among the interviewed patients is the value of cooperation between the multiple sclerosis patients and their neurologists. One patient shared their lived experience at the stage of receiving the diagnosis. The patient recalled:

“At the stage of the suspect of multiple sclerosis diagnosis I had very close cooperation with my neurologist. I remember when my neurologist entered my room, sat on my bed, and started to explain what it means to have multiple sclerosis. It was eleven years ago, a time when little was known about multiple sclerosis, and little did I know what MS means and how it changes

lives. The doctor said that it is unpleasant, but people with this disease can live long if following the recommendation of the healthcare professionals. We communicated very close all the following years. When my daughter was born the doctor got the role of Godmother for my daughter. I am very grateful for everything my doctor has done for me. Those words of encouragement at the beginning valued a lot for me and helped me to go through difficult times as well.”

Another patient also commented:

“The doctor that announced the diagnosis did a great job at that time. The doctor explained to me in detail everything about MS and had enough patience to answer all my questions, and there were many. It was a tough moment when I received the diagnosis but thanks to my doctor, I managed to go through that.”

The value of cooperation was also identified in the situation when the patients shared that their doctors were not cooperating at all. One patient shared the following:

“At the stage of the primary diagnosis when I got so scared about the diagnosis I have got and how my life is going to be after. I was so young back then. I was only twenty-one years old at that moment. The doctor asked me if I wanted to get a degree of disability. It offended me because it was not recommended because of my physical state. I was quite well physically at that moment. The doctor suggested that I get a disability degree because I would get a monetary reward for this. You can imagine how “encouraging” it can be for a young person in his early twenties to receive a question regarding the disability degree. I assume it was only with good intentions, but what I needed most at that moment was a bit of encouragement and cooperation.”

All ten interviewed patients mentioned the importance of cooperation between them and their healthcare provider. It can be said that it is obvious because cooperation is a common activity for all five customer value cocreation practice styles discussed by McKennedy et al. (2012).

All patients are different and communicate in different styles about their needs. It was also interesting to hear the perspective on cooperation from the doctor's perspective who commented:

"I always try to do my best to be available when patients need me. What is important here is that patients speak and tell me what they need and what is important to them. Yes, we are busy with all the administrative tasks, papers, and other stuff, but I am always happy to be helpful. My advice for the MS patients is to not be afraid to speak up and be proactive concerning their needs!"

4.3 Avoidance

The key activity that is very important for the success of the treatment for multiple sclerosis and not only, from the interviewed neurologist's perspective is the acceptance of the diagnosis. The doctor commented:

"The thing that I consider is up to the patients and could increase their quality of life is the acceptance of the reality, I mean a diagnosis of multiple sclerosis. I had a lot of cases in my experience when the patients did not want to accept the reality of the multiple sclerosis diagnosis, did not see any need in following the treatment which had led to worsening their health situation due to relapses that were not treated properly. I would say that acceptance and the correct diagnosis at an early stage are the two key aspects that could have a positive impact on the long-term health outcomes of the patients."

The theme of avoidance was also present in the responses of the patients. One patient commented:

"I do not have a magic pill of how to overcome difficulties after the relapses. I guess that the thing that helped me is that I use to ignore the information or facts that I don't like, especially at the very beginning when I received the diagnosis."

A similar answer was received from another patient who said:

“I don’t go to the hospital. I don’t like it. Why should I go? When I go to the hospital, I see other patients and hear their problems. It is very hard for me to see multiple sclerosis patients whose health outcomes get worse by each year. It really has a negative influence on me. I feel that if I don’t see them, then they are less. I know that’s not true, but at least it helps me to preserve my mental health.”

Another patient responded that:

“At the very beginning, it was very hard to accept the diagnosis of multiple sclerosis. I remember the moment when I received the diagnosis, I went home, found a lot of horrifying information on the internet about the prognosis of multiple sclerosis. Honestly, on that day I thought that I would die the next day. The most harrowing question that kept coming to my mind was Why does it happen to me? Why me? So, the next time I met my neurologist and shared my concerns they said not to read all the information on the internet. I have to say that I really follow this advice and it helps. Maybe it is not the best attitude, but sometimes when you know less you sleep better.”

Other patients also mentioned that they tend to avoid social interaction, a patient shared that they have moments when they avoid meeting with their friends. Another patient shared that at the very beginning they tried to hide their diagnosis because they were afraid of losing the job. The activity of avoidance and role to control from a distance is typical for insular controlling practice style of co-creation value (McColl- Kennedy et al., 2012). For three patients out of ten interviewed it was identified this customer value co-creation practice style of insular controlling. Insular controlling practice style of customer value co-creation is the second most practiced style among the interviewed patients.

A sub-theme that emerged from the theme of avoidance is the lack of community.

- subtheme: lack of the community

Patient community is a very powerful tool for patients to be heard. According to the European Multiple Sclerosis Platform, there are more than 1.2 million people living with MS that are

united in patients' association groups in Europe. Through these patients' association groups these patients have a real voice in advocating for their needs and determining their priorities. A situation that was identified to be almost missing among the MS patients in Moldova. Most of the interviewed patients do not communicate with other MS patients. Three out of ten interviewed patients said that they do not even know anyone in-person living with MS in Moldova. One patient answered the question regarding if they communicate with other people diagnosed with multiple sclerosis in Moldova, the following:

“I do not know anyone diagnosed with MS in Moldova. I am following a person with MS from Russia on YouTube. To be honest, I am so grateful that they share what they are going through. At the same time, I have to admit that I would not have enough courage to speak about my diagnosis and symptoms so openly to unknown people, moreover on social media.”

Another patient answered something similar:

“A few weeks ago, I saw an interview with a neurologist and a patient diagnosed with multiple sclerosis from Moldova on TV. I was surprised to hear that there are so many patients, more than one thousand if I recall correctly, with MS in Moldova. I thought it was a very rare disease because I don't know anyone in person with this diagnosis.”

The other seven patients, even though they know a few people living with MS in Moldova are not active in any patients' association group, despite the fact that a patients association group has existed since 2015. One patient commented:

“I know there is a multiple sclerosis patients' organization in Moldova, but it is not active. At least as far as I know. Well, I know it was a period when the organization was quite active, due to a grant from Soros. They were organizing different meetings and events. To be honest, I don't really see the meaning and purpose in all of these activities. They used to come, meet and discuss different things, but nothing really changed regarding the new options in the treatment of the disease.”

Another patient commented:

“Yes, I know a few people diagnosed with MS in Moldova. We stay in touch with them. Regarding the patient’s association, well, all of us are busy with our stuff and we don't have time for it. Also, most of us (I mean MS patients) encounter difficulties with walking, that's another reason why we can't meet in-person, moreover organize events.”

4.4 Power of communication:

The power of communication was highlighted both by the patients and by the interviewed neurologist. The neurologist also talked about the importance of trust for an engaged dialogue. Patients shared that when they trust their doctors, they can ask different questions or even uncomfortable ones. A sub-theme that emerged from the theme of communication is a psychotherapist.

- sub-theme: psychotherapist

The need for counseling by the psychotherapist was identified to be a common need for most of the patients. One patient commented:

“Psychotherapist counseling would be very beneficial because many patients are mentally affected after the received diagnosis of multiple sclerosis. Doctors in most of the cases do their best to take the role of the psychotherapist because they see how much need is in this.”

Another patient also said:

“Definitely, psychotherapist counseling is very important and every patient with MS needs it. Even me, I feel like depression is expecting me after the corner. Coming back to psychotherapists, it would be very good if patients with MS could have this opportunity, but please it should be called different. I would be a bit ashamed to say that I am going to the session with my psychotherapist. It should be called another way. I do not know exactly how, but definitely not a psychotherapist.”

All ten multiple sclerosis patients who were interviewed answered that the service of psychotherapists on a regular basis would increase their quality of life. The interviewed neurologist added on the importance of a psychotherapist as well but additionally talked about the need for the social assistant for MS patients.

Based on the highlighted need of a psychotherapist it can be inferred that the cerebral activities such as positive attitude, emotional labor and reframing, and sense-making is an activity that will positively impact the quality of life of MS patients. MS patients are struggling with doing this activity on their own and that's why a psychotherapist could guide and help them to implement it.

Cerebral activities (positive attitude, emotional labor, reframing, and sense-making) are common activities for the following customer value co-creation practice styles: team management, insular controlling, partnering, and pragmatic adapting (McColl-Kennedy et al., 2012). According to the same paper, cerebral activities are not common for passive compliance co-creation practice style. Contrary to what the outcomes of the interviews with MS patients revealed. According to the MS patients' answers, cerebral activities turned to be common for passive compliance as well.

When MS patients were asked to rate their quality of life, most of the interviewed multiple sclerosis patients chose moderate or high for psychological, existential, and support domains. The domain that was rated the most poorly is the physical one. It happens because of the patients' concerns and difficulties caused by fatigue, pain, weakness, and tiredness. These are the symptoms with which MS patients have to learn how to live every day. One patient commented:

“The hardest thing for me on my path with the multiple sclerosis diagnosis was and still is learning how to live with the pain in my whole body and tiredness every day. I guess because of the pain I feel in my body, sometimes I might seem aggressive, which is actually not true.”

Chapter 5: General discussion

5.1 Answering the research question

Value co-creation is a key concept of service-dominant logic and is defined as the “joint creation of value by the company and the customer. It is creating an experience environment in which consumers can have active dialogue and co-create personalized experiences” (page 8, Prahalad and Ramaswamy, 2004). From the service-dominant perspective, co-creation requires direct interaction between the customer (patient in the healthcare context) and the firm (the healthcare professional in the healthcare context). In other words, co-creation is joint value creation by the doctor and the patient.

According to Gronroos and Voima (2013), during the value co-creation process, the customer (or patient in the context of this paper) is the value creator, but when the firm (or healthcare provider in the context of this paper) takes part in the process (so enters the patient’s life), value is co-created with the provider. The real value is created in this set of direct interactions.

Patients may co-create value through five customer value co-creation practice styles, through adopting different roles (McColl-Kennedy et al., 2012). Patients may take the following roles:

- to assemble and manage a team in case of team management practice style;
- to control from distance in case of insular controlling practice style;
- to partner in case of partnering practice style;
- to adapt in case of pragmatic adapting practice style;
- to comply in the case of passive compliance practice style.

According to the same paper by McColl-Kennedy et al. (2012), patients co-create value through activities as cooperating, collating information, combining complementary therapies, co-learning, changing ways of doing things, connecting, co-production, and cerebral activities (positive attitude, emotional labor, reframing, and sense-making).

The prospective benefits of participating in a value co-creation process for customers are better quality of life (Street and Voist, 1997) and increased patient satisfaction (Lorig et al., 2008; Jahng et al., 2005).

In the empirical part of this paper, it was identified that MS patients are most likely to co-create value through passive compliance practice style (four patients), taking the role to comply with their healthcare provider. The second most common practice style among interviewed multiple sclerosis patients was identified to be insular controlling (three patients) and patients most often tend to adopt the role of controlling from a distance. The third most common co-creation practice style was identified to be pragmatic adapting (two patients), and team management (one patient). None of the interviewed patients co-create value through the partnering value co-creation practice style, see Table 9.

Table 9
Summary of Interviews with MS patients

#	MS type	Sex	Age	Employment	Stage	Phase	CVCPS
1	SP	M	33	Yes	11 yrs	No treatment	insular controlling
2	RR	M	33	No	9 yrs	Vit D	team Mn
3	RR	M	34	No, due to disability	12 yrs	Yes	passive compliance
4	PP	F	34	No	7 yrs	No treatment	passive compliance
5	RR	M	36	Yes	11 yrs	Vit D, E, B	pragmatic adapting
6	SP	M	42	Yes	12 yrs	Yes	insular controlling
7	RR	F	47	No	16 yrs	Yes	passive compliance
8	RR	F	41	Yes	11 yrs	Yes	Insular controlling
9	RR	F	31	No	9 yrs	Yes	Pragmatic adapting
10	RR	F	56	Yes	34 yrs	Yes	passive compliance

MS patients mostly focus on activities such as cooperating and engaging in collating information. At the same time, due to the neurological impact of the disease, they are inclined to be self-focused, stay alone and avoid social contact. The number of interactions of multiple

sclerosis patients is quite limited only to their neurologist and just in a few cases, it was mentioned the interactions with the family members.

At the beginning of the research, it was expected that the MS type will have a direct impact on the quality of life of the patients and their willingness to be proactive and engagement in value creation. It was assumed that patients with PPMS and SPPP will be less willing to take part in the value creation and will have a lower satisfaction of their quality of life, because of their poor health status, as these types are the most disabling. On the other hand, it was expected that patients with the RRMS type will be more open for co-creation and will have a higher satisfaction of their quality of life. It can be seen in the Table 10 that most of the patients diagnosed with RRMS tend to have moderate to high satisfaction of their quality of life, but only two out of seven interviewed patients with RRMS have willingness to be proactive. In the same time patients with SPMS and PPMS, two out three interviewed have a moderate level of satisfaction and also two of three have willingness to be proactive.

Table 10
Patients' MS type and their quality of life and willingness to be engaged in co-creation

Type of the MS, the patient has	Quality of life (overall)	Willingness to be proactive
SP	Low to moderate	Yes
RR	Moderate to high positive	Yes
RR	Low negative to moderate	No
PR	Moderate	Yes, but there are limitations due to the disability (patient is in the wheel chair)
RR	Moderate	Yes
SP	Moderate	No
RR	Moderate	No
RR	High positive	No
RR	Moderate to high positive	No
RR	Moderate	No

5.2 Comparison of the interview results of this paper and the outcomes of the study by McColl-Kennedy et al. (2012)

It was expected at the beginning of the research that the results of MS patients' interviews will differ from the outcome of the cancer patients investigated in the study by McColl-Kennedy et

al. (2012). The actual result of this paper showed that MS patients co-create value through passive compliance practice style and the most common activity is collating information, the same as cancer patients. The differences are in the impact of the physical domain that seems to have a bigger impact in the case of MS patients, please see Table 11. Even though MS patients may rate their psychological, existential, and support domains relatively high with moderately to high positive, the physical domain most of the time is rated poorly. A fact that is different from the outcomes of the McColl-Kennedy et al. (2012) paper which shows that cancer patients usually if rate physical domain poorly then they will rate poor on an additional domain as well.

Table 11
Comparison of the quality of life of MS patients and the patients in the McColl-Kennedy et al. (2012) study

Customer Value Co-creation Practice Style	Patients' Quality of Life in the study by McColl-Kennedy et al. (2012)	MS Patients' Quality of Life research in this paper																
Team Management	<table border="1"> <tr> <td data-bbox="529 953 748 1010">Psychological</td> <td data-bbox="748 953 1016 1010">High positive</td> </tr> <tr> <td data-bbox="529 1010 748 1100">Existential</td> <td data-bbox="748 1010 1016 1100">Moderately to high positive</td> </tr> <tr> <td data-bbox="529 1100 748 1157">Support</td> <td data-bbox="748 1100 1016 1157">High positive</td> </tr> <tr> <td data-bbox="529 1157 748 1247">Physical</td> <td data-bbox="748 1157 1016 1247">Low to moderately negative</td> </tr> </table>	Psychological	High positive	Existential	Moderately to high positive	Support	High positive	Physical	Low to moderately negative	<table border="1"> <tr> <td data-bbox="1032 953 1252 1010">Psychological</td> <td data-bbox="1252 953 1487 1010">Positive</td> </tr> <tr> <td data-bbox="1032 1010 1252 1100">Existential</td> <td data-bbox="1252 1010 1487 1100">Positive</td> </tr> <tr> <td data-bbox="1032 1100 1252 1157">Support</td> <td data-bbox="1252 1100 1487 1157">High positive</td> </tr> <tr> <td data-bbox="1032 1157 1252 1247">Physical</td> <td data-bbox="1252 1157 1487 1247">Moderate</td> </tr> </table> <p data-bbox="1032 1247 1487 1293">(1 patient)</p>	Psychological	Positive	Existential	Positive	Support	High positive	Physical	Moderate
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Insular Controlling	<table border="1"> <tr> <td data-bbox="529 1346 748 1423">Psychological</td> <td data-bbox="748 1346 1016 1423">Moderately negative</td> </tr> <tr> <td data-bbox="529 1423 748 1514">Existential</td> <td data-bbox="748 1423 1016 1514">Low positive</td> </tr> <tr> <td data-bbox="529 1514 748 1604">Support</td> <td data-bbox="748 1514 1016 1604">Low positive</td> </tr> <tr> <td data-bbox="529 1604 748 1694">Physical</td> <td data-bbox="748 1604 1016 1694">Low to moderately negative</td> </tr> </table>	Psychological	Moderately negative	Existential	Low positive	Support	Low positive	Physical	Low to moderately negative	<table border="1"> <tr> <td data-bbox="1032 1346 1252 1423">Psychological</td> <td data-bbox="1252 1346 1487 1423">Moderately to high positive</td> </tr> <tr> <td data-bbox="1032 1423 1252 1514">Existential</td> <td data-bbox="1252 1423 1487 1514">Low to moderately</td> </tr> <tr> <td data-bbox="1032 1514 1252 1604">Support</td> <td data-bbox="1252 1514 1487 1604">Moderate to high positive</td> </tr> <tr> <td data-bbox="1032 1604 1252 1694">Physical</td> <td data-bbox="1252 1604 1487 1694">Low to moderately</td> </tr> </table> <p data-bbox="1032 1694 1487 1745">(3 patients)</p>	Psychological	Moderately to high positive	Existential	Low to moderately	Support	Moderate to high positive	Physical	Low to moderately
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Pragmatic Adapting	<table border="1"> <tr> <td>Psychological</td> <td>Moderately positive</td> </tr> <tr> <td>Existential</td> <td>Moderately positive</td> </tr> <tr> <td>Support</td> <td>Moderately to high positive</td> </tr> <tr> <td>Physical</td> <td>Low to moderately negative</td> </tr> </table>	Psychological	Moderately positive	Existential	Moderately positive	Support	Moderately to high positive	Physical	Low to moderately negative	<table border="1"> <tr> <td>Psychological</td> <td>Moderately</td> </tr> <tr> <td>Existential</td> <td>Moderately to high positive</td> </tr> <tr> <td>Support</td> <td>Moderately to high positive</td> </tr> <tr> <td>Physical</td> <td>Moderately to high positive</td> </tr> </table> (2 patients)	Psychological	Moderately	Existential	Moderately to high positive	Support	Moderately to high positive	Physical	Moderately to high positive
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Passive Compliance	<table border="1"> <tr> <td>Psychological</td> <td>Low positive</td> </tr> <tr> <td>Existential</td> <td>Low positive</td> </tr> <tr> <td>Support</td> <td>Low to moderately positive</td> </tr> <tr> <td>Physical</td> <td>Low to moderately negative</td> </tr> </table>	Psychological	Low positive	Existential	Low positive	Support	Low to moderately positive	Physical	Low to moderately negative	<table border="1"> <tr> <td>Psychological</td> <td>Low to moderately positive</td> </tr> <tr> <td>Existential</td> <td>Low to moderately positive</td> </tr> <tr> <td>Support</td> <td>Moderately to high positive</td> </tr> <tr> <td>Physical</td> <td>Low negative to moderately</td> </tr> </table> (4 patients)	Psychological	Low to moderately positive	Existential	Low to moderately positive	Support	Moderately to high positive	Physical	Low negative to moderately
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5.3 Academic Implications

This master thesis adds to academic theory how patients with chronic diseases such as multiple sclerosis contribute to co-creation together with healthcare professionals leading to a better quality of life and health in general, by continuing the discussion on cancer patients value creation researched by McColl-Kennedy et al. (2012).

Therefore, this master thesis contributes to the existing literature by first identifying the most suitable customer value co-creation practice style (passive compliance), most commonly used

activity (collating information and cooperation), and most frequently interaction which are (primarily with the HCPs) in the real-world setting.

Second, as it is an interdisciplinary paper, it offers additional insights into the medical literature about multiple sclerosis. This master thesis contributes to the medical field with activities (collating information and cooperation) that have an additional positive effect on the course of the disease besides the prescribed medications. It offers insight into marketing on the co-creation concept in the healthcare industry, so also the other way around.

The third contribution of the thesis is the social one. It answers the call by the American Marketing Association “to drive positive change and have a bigger contribution to a better world through Marketing” (Chandy et al., 2021) by making this world a better place for MS patients. The authors of the paper *Better Marketing for a Better World*, discuss that today’s business challenges should also meet the needs of society due to environmental change. They highlight the importance of using the marketing tools to impact the outcomes beyond the financial goals of the firm because the path to maximizing the business goal is value-laden. This master thesis answers the recommendation of the paper by Chanty et al., (2021) concerning the importance of connection points through which customers (MS patients in the case of this paper) and the firm (HCPs and managers of the medical institution) share their resources (experience, knowledge, etc.). As the result, there will be win-win outcomes for all the shareholders (customers, employees, suppliers, communities, etc.). Based on the outcomes of the interviews with the MS patients and the neurologist it is obvious, that in case of closer collaboration there will be achieved a higher quality of life for MS patients. This is in line with the main idea of the paper by Chanty et al. (2021) that states “We can do more. We can do better. Let’s work together to develop better marketing for a better world.”

5.4 Managerial implications

First of all, as the central actors of this paper are MS patients, the implications of the results of this thesis are for them. MS patients from Moldova might use the results of this paper in their further communication when aiming to advocate for their needs with healthcare professionals.

Second, the results of this paper have implications for managers of the medical institutions treating MS patients. As it was identified that the most common customer value co-creation practice style (McColl- Kennedy et al., 2012) for MS patients is passive compliance. Meaning that there is room left for helping patients in their journey of adapting the team management or partnering practice style that leads to a better quality of life.

It also offers healthcare providers insights from the patients' perspectives on how important are the words of encouragement at the stage of the primary diagnosis of MS and after. These words of encouragement help the doctors building a more trustful relationship with their patients that contributes positively to an engaged dialogue.

The implication of this paper is also for the healthcare industry as a whole. From one side this paper emphasizes the need the changing the public health policy (in the real setting of multiple sclerosis) and from the other side, it accentuates the importance of patient empowerment. If empowering the patients to take part in value co-creation it will help also the healthcare professionals in their duty of serving the patients the best they can.

5.5 Recommendations

Based on the insights of the interviews a few recommendations can be taken under consideration by the participants of the value creation process in healthcare:

- a) Medical institution managers could implement as mandatory the activity of cooperation and words of encouragement for MS patients in the medical institution. Another step that could be taken by the medical institution managers would be to hire a psychotherapist that will help MS patients in their cerebral activities.
- b) The healthcare system could start considering building a multiple sclerosis center with specialized neurologists mainly in MS, with a kinetic therapist and a psychotherapist. This will be helpful for the doctors in their journey of effectively serving their customers.
- c) As it was stated earlier in this paper in the process of value creation, the customer should adopt the role of co-creator. To evolve in this direction MS patients should also make an effort to adjust their role to the co-creator of value and engage in more activities. As the results of the interview with the neurologist disclosed the importance of patient voice

and that they should ask for what they need. MS patients could treat the results of this master thesis as an additional call to become proactive by increasing the power of their stories (Ellis, 2021) towards disease awareness and patient voice power among the general population, HCPs, and policy decision-makers.

5.6 Limitations

This master thesis focuses on value co-creation in healthcare organizations. From the theoretical aspect, it researched value co-creation, defined the actors of the co-creation process, their roles, activities, and interactions. The practical research comes up with suggestions for healthcare organizations from the point of view of MS patients from Moldova and what they consider to be important in the co-creation process between healthcare professionals and MS patients. A limiting factor here could be considered the geographic aspect, as the sample of the respondents included only residents from Moldova. Perhaps respondents from other countries may have a different perspective.

Another limitation which this paper has and is typical for qualitative analysis is the researcher bias. Perhaps with two or three researchers, the drawn conclusions could be different.

Also, this master thesis does not focus on the effectiveness of the medication taken by the patients and how a certain type of medication may influence the quality of life of the patients. The financial benefits of implementing any of the researched value co-creation practice styles (CVCPS) were not addressed in this paper as well. As for this stage, this paper did not include the impact of digital tools as apps.

The main goal of this research is the aspect of quality of life of multiple sclerosis patients and identifying the interactions and activities that will lead to a better quality of life for these patients.

5.7 Future research ideas

In this final section, we outline an agenda for future research. The paper provides the following research ideas on the practices of customer value creation:

- (1) application among other ongoing diseases. Even though we assume that chronic diseases may have a lot in common, the results of this paper do not include the ideas of other patients' groups besides MS patients.
- (2) future research on benefits for physicians and what would motivate them to invest in value co-creation.
- (3) changes in the financial aspect if implementing value co-creation in the medical institutions.
- (4) due to the covid-19 pandemic, the whole World went through a transformation and an accelerated digitalization. An idea for future research would also be to investigate whether digital tools could help the patient and healthcare providers in the value co-creation process.
- (5) how could doctors empower patients to be more active and open in order to gather and form a community that will have a real voice in advocating for their needs.
- (6) multiple sclerosis is one of the most disabling neurological diseases. Quite often after a few years of living with MS, patients are unable to participate in their health care management and their family members act on the patients' behalf. Future research could investigate the role of third parties in the value co-creation process.

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Appendix A

Interview Protocol Guide- MS patients

The interviews will be conducted to gather information on the experiences of the MS patients with their healthcare providers. The structure of the interview has the aim to facilitate reflection of those experiences. The master student will encourage the patient in a comfortable manner to share their experience with healthcare professionals before the MS diagnosis and after.

Before proceeding to the interview, the patient will read the consent form (Appendix B) form and only if they agree they may take part in the interview.

The next step is the interview itself (Appendix C). The questions used for this interview are based on two papers McColl-Kennedy et al. (2012) and Dunning (2020).

Questions from part A are supposed to have short answers and the objective is to gather the information that could create a certain frame of the patient that will be interviewed further. The questions from part B are open questions that have the goal to gather information on past and present experiences with the healthcare providers in an elaborated way.

Appendix B

Respondent consent form

Dear respondent,

You are invited to participate in this interview as a scope of my master thesis at the Erasmus University Rotterdam, with the topic *What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?*

Master student: Victoria Priscu, contact email: 570915vp@eur.nl

Purpose of the research question: Multiple sclerosis is the most disabling neurological disease among young adults. As for now, there is not any treatment that could cure this disease but only to increase the quality of patients' life. Besides this, we see the potential of improving the lives of people living with MS through value co-creation with their healthcare providers. The objective of this master thesis is to identify the suitable co-creation practice style for people living with MS that could lead to an increased quality of life.

Benefits for participating in the interview: people living with MS are the main actors in the interactions between MS patients and healthcare providers. That's why it is very important to gather information mainly from them. People living with MS will have one more chance to speak up about their needs and ideally to make their voices be heard.

The setting of the interview: it will be held online, using a zoom meeting. In case of your consent, the interview will be recorded. In case interviews will be held offline, the researcher will take notes during the interview, if the respondent agrees with that.

Confidentiality:

- The identity of the respondent will be known only by the research, and will not be shared with anyone. In the research itself, the name of the respondent will change with a nickname or #001, #002, #003
- Immediately after the interview procession, the recording will be deleted. Further, the answers provided will be processed anonymously.
- Respondent participation is voluntary and they have the right to answer only the question they are comfortable with
- Respondent reserves the right to withdraw from participating in the research anytime, before the 30th of June. After that date, some data usage and dissemination may happen and it will not be possible to withdraw.

Follow up: If interested in the results of this research please contact Victoria Priscu by email at Victoria.priscu@gmail.com

As a consent for participating in the interview, and that you have read and understood the information provided in this consent form we will consider the case of answering positively to the email which has this form attached.

Appendix C

Interview questions funnel

Dear respondent,

Thank you for accepting to participate in the interview which aims to collect the data for my master thesis *What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?*

The interview might take from 60-90 minutes, but you may withdraw or ask for a break any time you wish to do so. Also, as it was mentioned in the consent form all the answers you provide are anonymous and will also be processed anonymously.

Part A

	Respondent answer
1. Type of MS	
2. Sex	
3. Age	
4. Employment	
5. Stage (a year since the first diagnosis of MS)	
6. Phase (receiving any treatment or not)	
7. How often do you see your neurologist?	

Part B

Question on which to elaborate more:

8. What is MS from your perspective? (Dunning, 2020)
9. Tell your story in your own words? (McColl-Kennedy et al, 2012)
10. When you were first diagnosed with MS and how you felt? (McColl-Kennedy et al, 2012)
11. Your experiences at various stages: How do you get through those times? What sort of things have you changed in your life? (McColl-Kennedy et al, 2012) How your life has changed after your MS diagnosis? (Dunning, 2020)
12. What has been the hardest thing for you on your path with MS? (Dunning, 2020)
13. How has the HC system worked with you during the stage of the MS suspect? (Dunning, 2020)
14. What were your impression and experiences prior to the MS diagnosis with the healthcare system? (Dunning, 2020)
15. How have you and your family been treated over time by healthcare providers? (Dunning, 2020)
16. Activities and interactions around perceptions of the provider's and patient's role (McColl-Kennedy et al., 2012).

During the interview to find out the number of interactions, and activities and make the link to the customer value co-creation practice style (CVCPS):

Activities & interactions	Quotes of the patient	CVCPS
<p>High level of activities (cooperating, collating information, co-learning, combining complementary therapies)</p> <p>High level of interactions (connecting with family, nurses, doctors, self-generated activities)</p>	<p>Role of the patient to assemble and manage the team</p> <p>Patient's quotes:</p> <p>_____</p> <p>_____</p>	<p>Team management</p>
<p>Low level of activities (cooperating and collating information)</p>	<p>Role to comply.</p>	<p>Passive compliance</p>

<p>The low number of interactions (primarily with the doctors)</p> <p>This practice style is characterized by acceptance. Patients tend to not question the doctors</p>	<p>Frequently patients say to the doctor “you know the best”</p> <p>Patient’s quotes: _____ _____</p>	
<p>Medium level of activities (collaboration is typical with doctors and limited number of professionals, collating information, combining therapies)</p> <p>Medium level of interactions</p>	<p>Role to partner. Patients frequently ask for listening and communication with their doctor</p> <p>Patient’s quotes: _____ _____</p>	<p>Partnering</p>
<p>High level of activities (cooperating, collating information, co-learning, combining complementary therapies), but they are not open as in team management</p> <p>A low number of interactions (those which exist are superficial). Patients tend to be self-focused. They prefer to be alone and not share their feelings and their experience with the symptoms of the disease</p>	<p>Role to control from a distance. Patients tend to avoid social content, sometimes they may not even walk in their neighborhood.</p> <p>Patient’s quotes: _____ _____</p>	<p>Insular controlling</p>
<p>Low level of activities (cooperating, collating information, and connecting). Patients tend to be changing and adaptive.</p> <p>High level of interactions with different individuals. Patients do not hide from others and do not feel ashamed of who they become after the diagnosis.</p>	<p>Role to adapt to the changed circumstances.</p> <p>Patient’s quotes: _____ _____</p>	<p>Pragmatic adapting</p>

During the interview, using the table above and based on the level of interactions, and activities, and the way they see their role to conclude on a certain CVCPS.

17. Could you please kindly describe your recent visit to your neurologist? Maybe you could elaborate on 1 positive and 1 negative aspect from your point of view (Dunning, 2020)
 18. What are the healthcare services you are receiving from the clinics now? (McColl-Kennedy, 2012)
 19. How would you define your quality of life? (McColl-Kennedy, 2012)
-

How would you assess your quality of life on 4 dimensions while using 3 levels: low, moderate, or high?

	Low	Moderate	High
Psychological			
Existential			
Support			
Physical			

20. How satisfied are you with the health outcomes at this moment (McColl-Kennedy, 2012)
21. Additional relevant questions used during the interview _____

Appendix D

Interview Protocol Guide- Healthcare professionals

The interviews will be conducted to gather information on the relationship between the MS patients and their healthcare providers. The structure of the interview has the aim to facilitate doctors' reflection of those interactions and communication that usually occurs between the HCPs and their patients. Before proceeding to the interview, the HCP will be asked to read the consent form (Appendix E), and only if they agree they may take part in the interview.

The next step is the interview itself (Appendix F). The questions used for this interview are based on the Dunning (2020) paper.

Appendix E

Respondent consent form- neurologist

Dear respondent,

You are invited to participate in this interview as a scope of my master thesis at the Erasmus University Rotterdam, with the topic *What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?*

Master student: Victoria Priscu, contact email: 570915vp@eur.nl

Purpose of the research question: Multiple sclerosis is the most disabling neurological disease among young adults. As for now, there is not any treatment that could cure this disease but only to increase the quality of patients' life. Besides this, we see the potential of improving the lives of people living with MS through value co-creation with their healthcare providers. The objective of this master thesis is to identify the suitable co-creation practice style for people leaving with MS that could lead to an increased quality of life.

The setting of the interview: it will be held online, using a zoom meeting. In case of your consent, the interview will be recorded. In case interviews will be held offline, the researcher will take notes during the interview, if the respondent agrees with that.

Confidentiality:

- The identity of the respondent will be known only by the research, and will not be shared with anyone. In the research itself, the name of the respondent will be changed with a nickname or #001, #002, #003
- Immediately after the interview procession the recording will be deleted. Further, the answers provided will be processed anonymously.
- Respondent participation is voluntary and they have the right to answer only the question they are comfortable with
- Respondent reserves the right to withdraw from participating in the research anytime, before the 11th of July. After that date, some data usage and dissemination may happen and it will not be possible to withdraw.

Follow up: If interested in the results of this research please contact Victoria Priscu by email at Victoria.priscu@gmail.com

As a consent for participating in the interview, and that you have read and understood the information provided in this consent form we will consider the

case of answering positively to the email which has this form attached.

Appendix F

Interview questions funnel- neurologist

Dear respondent,

Thank you for accepting to participate in the interview which aims to collect the data for my master thesis *What type of activities and interactions between MS patients and their physicians (HCPs) from a patient perspective will lead to a better quality of life for MS patients?*

The interview might take from 60-90 minutes, but you may withdraw or ask for a break any time you wish to do so. Also, as it was mentioned in the consent form all the answers you provide are anonymous and will also be processed anonymously.

1. From your perspective, how do you feel multiple sclerosis impacts the lived experience of your patients? What are some of the factors you feel influences the variability in the patients with multiple sclerosis you see?

Age? - Family support? - Profession? - Activity level?

2. What do you believe is the hardest thing about having multiple sclerosis for MS patients?
3. How often do you meet with your patients? What are some of the recurring concerns your patients share with you?
4. Do you have a sense of what patients are expecting when they meet with you? During the meeting who talks more? How do you feel about that?
5. In general, how would you describe your relationship with your patients?
6. Do you feel your patients are able to ask and act on your advice?
7. Do your patients ever disagree with your advice?
8. Overall, are there things you can identify that have led to good relationships with your patients?
9. Are there any factors you can identify that may compromise your relationship with your patients?

10. In the work, you do with patients how important is trust? Given how often you meet your patients and the time you get to work with them, do you feel you have the time to build a trusting relationship?
11. Is there anything you expect from your patients, that you consider is up to them that could increase their quality of life?
12. What are some of the critical limitations that impede your work with multiple sclerosis patients? How would you prefer they were solved?
13. What is the most difficult thing about your work that you wish your patients could understand? What could our healthcare system do better to improve your practice and the health of your patients?
14. What are some things patients can do to reliably improve their healthcare experience? Patterns you have observed, must account for, challenges to help them?
15. In terms of the relationship with your patients is there anything we missed that you want to discuss? Anything that you think we should consider?

Thank you for your time today!